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## Effects of Stigmatization on Gay Men Living with HIV/AIDS in a Central-Eastern European Context: A Qualitative Analysis from Hungary

J. Takács<sup>1</sup>, J.A. Kelly<sup>2</sup>, T. P. Tóth<sup>3</sup>, L. Mocsonaki<sup>4</sup>, and Y.A. Amirkhanian<sup>5</sup>

<sup>1</sup>Institute of Sociology of the Hungarian Academy of Sciences, Budapest, Hungary

<sup>2</sup>CAIR, Medical College of Wisconsin, US

<sup>3</sup>Institute of Sociology of the Hungarian Academy of Sciences, Budapest, Hungary

<sup>4</sup>Háttér Support Society for LGBT People, Budapest, Hungary

<sup>5</sup>CAIR, Medical College of Wisconsin, US & Botkin Hospital for Infectious Diseases, St. Petersburg, Russia

### Abstract

This qualitative study highlights the social dynamics affecting people living with HIV (PLH) in Hungary and in the Central-Eastern European region. The study focused on the special needs and concerns of men living with HIV/AIDS as well as changes in their social relationships and institutional support provision, coping strategies and patterns of social functioning, especially in the context of social stigmatization. Consistent with international qualitative research findings in the field of HIV/AIDS prevention, the present study contributes to a fuller understanding of relationship between sexual behavior, HIV/AIDS related risks and risk perceptions as well as homosexuality-and HIV/AIDS stigma-related social exclusion in a previously under-researched socio-cultural setting. The findings of our study point to several barriers to effective HIV prevention, which should be overcome to improve the present situation by lessening the adverse effects of HIV/AIDS-and homosexuality-related stigma within the gay community, the general population and especially among service providers. One of the main barriers is the lack of public health programs specifically targeting MSM in Hungary, where the predominant mode of HIV transmission remains sex between men.

### Keywords

HIV/AIDS; stigma; Hungary; Central-Eastern Europe; gay men; homophobia

### Introduction

HIV infection and sexually transmitted diseases (STDs) emerged as public health threats only in the last decade of the 20<sup>th</sup> century in many countries in Central and Eastern Europe. The region witnessed a rapid social transition in the 1990s from state socialism to consumer capitalism. During this process, increased personal freedoms, mobility opportunities and a liberalization of formerly conservative sexual behavior values were accompanied by increased drug use and a growth in commercial sex (Amirkhanian et al. 2009).

The collapse of the state-socialist regime was characterized by a marked decline in health status in Hungary, where life expectancy is still among the lowest in Europe (Gaál 2004). Unlike in several African, American, Asian, and some European countries, AIDS is still not considered to be a major health concern in Hungary. The first Hungarian HIV infection was identified in 1985 and, by September 30 2011, 2,075 HIV infections were officially registered (OEK 2011), although the true number is believed to be at least three times higher. According to UNAIDS (2010) estimates, 3,000 people were living with HIV in Hungary in 2009. In Hungary, the main risk factor for HIV infection is unprotected sex between men, while the number of infections caused by injection drug use remains very low (OEK 2011).

During the first decade of the 21<sup>st</sup> century, rates of HIV and STDs increased dramatically in many post-Soviet countries, including the Russian Federation and Ukraine, one of Hungary's neighboring countries (UNAIDS 2010). In other post-socialist countries adjacent to Hungary, including Croatia and Romania, no increase was observed. Between 2001 and 2009, the number of people living with HIV (PLH) increased from 1,900 to 4,900 in Serbia, from less than 200 to under 500 in Slovakia, and from fewer than 500 to under 1,000 in Slovenia (UNAIDS 2010). The estimated antiretroviral therapy (ART) coverage rate of PLH varies greatly in these countries ranging from 13% in Ukraine, 34% in Serbia, and 38% in Hungary to 69% in Romania and 81% in Slovakia (Havlíř – Beyrer 2012).

According to European data of the 2011 WHO Progress Report, rates of diagnosed HIV cases have doubled in Hungary as well as in Bulgaria, the Czech Republic, Lithuania, the Netherlands, Slovakia, and Slovenia (WHO 2011). In a 2010 resolution, the European Parliament stated that “there is strong evidence of HIV/AIDS prevention as an effective means to reduce new infections” (EP 2010), and emphasized the importance of fighting stigma and discrimination of PLH.

Within the relatively small Central-Eastern European area surrounding Hungary, distinct patterns of HIV transmission can be observed in different countries. For example, and as in many Eastern European and Central Asian countries, injection drug use is the predominant transmission mode in Ukraine. Nosocomial infection that affected mainly children in the late-1980s is a specific feature in Romania (Novotny et al. 2003). The highest male-to-female ratios of HIV infections diagnosed in 2010 were reported from countries where the predominant mode of transmission was sex between men, including Hungary (15.7) and Slovakia (8.3), relative to an overall ratio of 2.8 in Europe (ECDC 2011). Men who have sex with men (MSM) also account for the majority of registered HIV cases in Croatia and Slovenia (Štulhofer et al. 2008). The Hungarian, Czech, Slovakian, Slovenian and Croatian patterns of MSM transmission reflect the predominant reported mode of transmission in the European Union, accounting for 35% of the HIV diagnoses in 2009 (Likatavicius – van de Laar 2010). However, in Central and Eastern European countries, data on HIV epidemiology among MSM is more limited in comparison with other vulnerable groups. This has been attributed in part to the stigmatization of homosexuality in the region (Bozicevic et al. 2009; Rhodes – Simic, 2005; Štulhofer – Sandfort, 2005).

Specific health needs of MSM are not generally recognized in Central-Eastern Europe, and safer sex campaigns for MSM audiences are mainly conducted by lesbian, gay, bisexual and transgender (LGBT) civil organizations (Beaumont 2012). In Hungary, and apart from medical care, there are few institutional support networks organized for PLH. A small number of non-governmental organizations (NGOs), informal groups and activists maintain a HIV hotline, write high-quality interactive web-blogs, and organize regular personal encounters for PLH as well as their friends and family to provide up-to-date information and

psychological support. However, their resources are limited, they are mainly available in the capital city or on the internet, and not everyone can access their services (Takács 2007).

Prior studies have found that topics related to homosexuality and HIV/AIDS usually share a common “mainstream media fate”, portrayed as affecting other relatively powerless social minority groups, characterized by low visibility and behaviorally stereotyped (Gross 2002). One of the strongest stereotypes about homosexuality reinforced in Hungarian mainstream media is related to promiscuity. References to “homosexuals” being an “AIDS risk group” (the terms usually used by the media) played an important role in maintaining this stereotypical view. Same-sex behaving men have often been described as if they were all members of a uniform “risk group”, equally at risk for HIV/AIDS-infection (Takács 2007). Empirical research conducted in 1999 focused on the social representation of HIV/AIDS in five Central and Eastern European countries, including Hungary. Survey respondents were most likely to cite “homosexuals” as being a “high risk group”, and the most frequent free-associations with the word AIDS also included “homosexuals” (Goodwin et al. 2003; Goodwin et al. 2004).

Although same-sex activity of consenting adults was decriminalized in Hungary in 1961, there have been several manifestations of institutionalized discrimination against gay and lesbian citizens. These include the different ages of consent for same-sex and different-sex partners before 2002, and the present lack of legal institutions such as same-sex marriage or joint adoption by same-sex couples. After the postsocialist political system change, social attitudes towards homosexuality became somewhat more permissive (Takács 2007). However, empirical data of the European Social Survey conducted in 2008–2009 measuring the agreement level with the statement that “*gay men and lesbians should be free to live their own life as they wish*”, found that, among 26 European societies, the greatest level of social acceptance was expressed in Northern and Western European countries, while the lowest level of acceptance was expressed in eight postsocialist countries, including Hungary. Thus, in the European context, Hungary belongs to the more intolerant societies where acceptance of the freedom of gays and lesbians to live their own life as gays and lesbians is not at all well developed. This plays an important role in the mechanisms of social exclusion affecting gay men and lesbian women (Takács – Szalma 2011).

There is great scientific awareness about the difficulties caused by HIV/AIDS-related stigma and discrimination in HIV/AIDS prevention efforts. Stigmatization, through its serious disempowering effects on the stigmatized, can limit access to prevention and care services. Fear of discrimination can discourage people from being tested and, for those with positive HIV test results, may contribute to nondisclosure of HIV status to others including friends and sexual partners (Kegeles et al. 1989; Gilmore – Reynolds 1994; Alonzo – Reynolds 1995; Herek – Capitano 1999; Parker – Aggleton 2003; Herek et al. 2003, Klitzman et al. 2004; Klitzman et al. 2007; Earnshaw – Chandoir 2009; Stutterheim 2011). In the present study, HIV/AIDS stigma is interpreted as a socially constructed “undesired differentness”, perceived as a “blemish of individual character” which, in the course of the stigmatization process, can transform one’s identity into a “spoiled” one (Goffman 1963).

In countries such as Hungary, where MSM are the largest subgroup of HIV infected people (OEK 2011), HIV/AIDS-related stigma is closely associated with homosexuality-related stigmatization and discrimination. In these societies, gay men living with HIV/AIDS can thus experience a “layering of stigma” (Mill et al. 2010: 1471) in the sense that they are affected by stigmatization derived from fear of HIV as well as from an often moralizing disapproval of same-sex behavior.

## Purpose

The purpose of this study is to explore barriers to effective HIV prevention related to social stigmatization of PLH in Hungary. We use qualitative in-depth interviews to analyze the experiences and the social situation of men living with HIV infection to shed light on the contextual, attitudinal, social, and motivational factors affecting them, an approach rarely employed in Central and Eastern Europe, including in Hungary. The study aims to identify critical HIV/STD risk issues that need to be addressed in prevention programs and programs designed for MSM living with HIV/AIDS in the region.

## Methods

### Recruitment procedures

This study was carried out in Budapest, the capital city of Hungary, between April, 2007 and May, 2009. Budapest is a major metropolitan city with the largest gay community and the highest HIV rates in the country (OEK 2011). We employed snowball sampling (Goodman 1961), a chain-referral sampling method often used in social science studies to recruit members of hidden or hard-to-reach populations, where sampling frames do not exist, and where being publicly identified as a member of such populations can carry the risk of social stigma (Heckathorn 1997). In our study, seven MSM with HIV infection were initially recruited with the help of NGOs and HIV activists, and by advertising on relevant online forums and in a gay magazine. Following the initial recruitment of the first participants, already-recruited respondents helped to identify other PLH MSM and provided personal referral to those willing to take part in our study.

### Participants

The mean age of the 27 participants was 36 years (range 22 – 52). With respect to educational level, 17 participants had a university degree, 6 had completed secondary education, and 4 had only completed primary level education. 14 were permanently employed, 6 were unemployed, 6 received disability benefits because of their HIV status, and one was a student. All men in the sample identified as gay, and 16 of them reported having a committed relationship with another man. In 9 cases, the main partner of the respondent was also HIV infected. At the time of the interview, most participants lived in Budapest, which has the only Hungarian hospital that provides specialized treatment for patients with HIV. Most respondents moved to Budapest after discovering their HIV infection or always lived there; although 3 still lived in the countryside. 11 men cohabited with their same-sex partner, 9 lived in a single household, 3 were homeless and lived in shelters, 2 stayed with their parents, one rented a place with a friend, and one lived in a hostel. All but one participant described his ethnicity as white. That individual described himself as Roma (Gypsy). Two participants were foreign citizens living in Hungary with a residence permit. 21 participants had never been married; one was married but separated, while 5 were divorced. Three of the once-married participants also had a child.

### Interview procedures

The study was approved by the ethics committees of the Institute of Sociology of the Hungarian Academy of Sciences and the Medical College of Wisconsin. Potential interviewees were provided with an explanation of the study, and willing participants provided written informed consent. All interviews lasted 1.5 to 2 hours. Following semi-structured in-depth interviewing procedures, a standard topic guide was applied with open-ended questions around the main themes including relationship characteristics; HIV-infection perceptions, coping strategies, personal patterns of social relationships, institutional support, and personal experiences of stigmatization as well as discrimination.

Interviews were conducted in private one-on-one sessions by experienced interviewers. Each interviewee chose a pseudonym which, together with an indication of their age at the time of the interview, was used for their identification in the study. The interviews were tape-recorded with the agreement that all audio-material would be destroyed after transcription.

## Data analysis

The recorded interview material was first transcribed verbatim. Transcripts were transformed into a code book by applying structural coding, resulting in the identification of relatively large segments of interview texts that could later form the basis for a more in-depth analysis within and across topics (MacQueen et al. 2008). Structural coding can also enable quantitative applications to a certain extent. For example, on the basis of the number of participants referring to a given theme, different code frequencies could be determined that could help to identify common ideas emerging in the texts of more participants and distinguish them from rarely-mentioned ideas unique to specific respondents (LeCompte – Schensul 1999). The structural coding process started by creating a detailed list of structural coding categories based on the standard topic guide used during the in-depth interview sessions, reflecting the main themes of our research interest. All data that could be identified as being pertinent to certain coding categories were collected under the appropriate coding categories and subcategories resulting in a Hungarian code book, which was later translated into English.

The present data were produced by the qualitative analysis of this code book's contents of structurally-coded data following a qualitative methodological paradigm with an interactionist focus. Thus, we concentrated on meaning construction mechanisms and patterns emerging from the interpretations of respondents' views and lived experiences. With structurally coded data, the grounded theory method is also applicable (Saldaña 2009). Our data analysis procedures were based on grounded theory with the main goal to discover rather than to verify (Strauss – Corbin 1998). Data analysis was conducted by the application of investigator triangulation (Denzin 1989), practiced by a small team of three qualified researchers who participated in several individual and joint research analysis sessions. In this context, our method of analysis can be described as a collective effort to identify phenomenological explorations of meanings attached by our respondents to phenomena including HIV infection, AIDS, and stigmatization.

## Results

### HIV/AIDS stigma and social exclusion

References to concurrent experiences of both HIV/AIDS- and homosexuality-related stigmatization were present in our interview narratives. Previous research already highlighted that, similar to internalized homophobia, the internalization of the HIV stigma can also result in self-hatred (Herek 1990; Lee et al. 2002; Herek 2004). Both issues can be interwoven in a specific form of internalized homophobia based on the illusory inseparability of homosexuality and HIV/AIDS. One respondent described how he kept denying his homosexual feelings because of his dreadful fear of AIDS lasting many years: *I must have equated homosexuality with HIV infection in my mind, and it took me a long time to try disassociating the two... Non-stop fear of HIV was always there. ... By the time I finally managed to disengage the two [homosexuality and HIV], I got my positive HIV results...* (Rudolf 29).

More than half of the respondents stated that they personally had not experienced social exclusion related to homosexuality. However, most of these interviewees kept the same-sex attraction aspects of their lives concealed: *I haven't announced it [my homosexuality] with a*



*flourish of trumpets. Thus, I haven't experienced any discrimination* (Zotyá 41). Others reported several incidents of verbal abuse and a few cases of physical attacks in connection to their same-sex attraction. Several respondents confirmed previous findings emphasizing that “for gays and lesbians, abuse often begins at home” (Nardi – Bolton 1998:141). Homophobia in the family can develop into verbal as well as physical violence, and can lead to young people being thrown out of home or cause them to begin living a double life. Three of our respondents were thrown out of home at a young age, two of them were also disinherited. One of them summarized his forced coming out in the following way: [*When I was 18*] *once we had a walk with my father who asked me whether it is true that I am a faggot. Yes, I am, I said. Ok, he said, then you have 10 minutes to finish with it – because, according to my parents, it was like flu, which will pass... then I was thrown out and disinherited* (Edomer 38).

One of our respondents, whose HIV infection was discovered by accident before an operation, gave a vivid illustration of the dangers of putting the “whole AIDS issue” into a heteronormative morality context. He pointed to the potentially dangerous public health consequences of presenting HIV/AIDS as affecting mainly gay men because of their “immorality”: *When this whole AIDS thing was introduced [in the 1980s], it was done in a very blatantly vulgar way: saying that it affects only gays, and only men. It was presented in a very negative light, and as a moral question. And then it wasn't taken seriously by any of us, or just by a very few... I had heard of it [AIDS] but, because it was presented in this badly non-realistic way at the beginning, most of us thought that this disease simply does not exist. It is just impossible that there is a “seeing virus” which would target only us [gays] ... we just couldn't believe this* (Egon 40). Reliable information about the realities of contracting HIV/AIDS were thus lost or not taken into consideration because the moralistic overtones and the extreme constructions of homosexuality reduced a sense of personal relevance and identification with public health messages on HIV/AIDS issues.

As a general rule, most of our interviewees remained more secretive about their HIV status than their same-sex attraction. Keeping the “HIV secret” to themselves was seen as a practical strategy of self-protection, including those who were openly gay. One openly gay respondent described how he tries to avoid experiencing HIV infection-related social exclusion mechanisms by not confronting people with information on his HIV status:

This is a form of self-defense. If HIV infection would be something like being gay, I would come out with it... However, being HIV positive is a different matter, because it is about a contagious disease, which can be contracted, while being gay is not contagious. You can contract HIV, and this is a fact beyond dispute. In the case of gayness, I can bring up arguments why it is good, why it is OK to be gay, but I cannot say the same about HIV. I cannot say that HIV infection is not bad, because it is obviously bad. We all know that it is better to live without it than with it... If the whole town knows about my HIV status, then the dentist won't have me and people will avoid me on the street. ... So, I never inform anyone about my HIV status and, even if someone would directly ask about it, I wouldn't say anything because it is none of their business. (György 30)

The secretive route to self-protection is a well-known strategy for trying to avoid potential acts of discrimination. In this context, effects of the felt stigma can be seen as preventing the activation of enacted stigma (Jacoby 1994; Alonzo-Reynolds 1995). It is probably not a coincidence that, when asking about HIV/AIDS discrimination and stigmatization experiences, one of the most frequently mentioned contexts was the healthcare system because it is an environment where respondents' HIV status could not be concealed. Seriousness of the social stigma attached to HIV/AIDS in Hungary was also reflected by views of medical professionals directly involved in HIV/AIDS care who advised the

maintenance of secrecy concerning the patients' HIV status: *It was the first thing that was said by the doctor and also by the nurse [working at the HIV/AIDS ward] that I shouldn't tell anyone. (Rudolf 29).*

Our respondents' descriptions of insensitive and insensible healthcare practices included the following: *I go back for another examination [to a hospital], and the matron recognizes me: You are that faggot with AIDS, aren't you? Why don't you go to the X hospital [with a specialized HIV ward]? When I say that the consultant ordered me back, she asks whether I had a wash and whether I am clean, as if she didn't know the ways how this disease can spread (Krisztián 37).* Manifestations of various forms of antagonism by healthcare providers towards clients with HIV/AIDS, including negative attitudes, avoidance, awkward social interaction and expressions of feelings of discomfort encountered by our respondents, have been well-documented by previous studies (Kelly et al. 1987; Kegeles et al. 1989; Stutterheim et al. 2009; Obermeyer et al. 2011; Stutterheim et al. 2011).

### Effects of stigmatization on relationship patterns and coping strategies

Examination of respondents' social relationships before and after contracting HIV highlighted effects of stigmatization as reflected in the changing density and composition of their social networks. After learning about their HIV positive status, respondents' social relationships increasingly included institutional contacts with testing facilities and HIV/AIDS specialists as well as other HIV-infected clients of the healthcare system. Some of these new contacts allowed participants to learn to cope with HIV/AIDS stigma with the help of others who had gained more experience in managing stigma.

The age at which the interviewees first became aware of their HIV infection varied from 22 to 52: the longest period was 17 years and the shortest one was only one month. Thus, interviewees reported using different coping strategies and different levels of effort in trying to come to terms with their HIV infection.

### Changes in social relationships

Respondents initially had mixed circles of friends, but most had more gay than straight friends. For some interviewees, there was a clear distinction between lovers and friends while, for others, these seemed to be somewhat overlap. The definition of the "sexually transmitted friend" seemed to be a person who was met originally as a sex partner and later became a friend, as in this case: *Usually, I do not have sex with friends. However, there were some friends whom I originally met as a sex partner but later our relationship became friendship (Etele 52).*

The narratives also reflected a certain temporally- and technologically-determined evolution in ways to find and meet other gay men, starting in the early 1990s after the political system change that allowed more publicly accessible space for homoerotic practices. For at least one generation of gay men who became young adults in the 1990s, printed ads were the most effective way to find gay partners: *At the beginning, there was the magazine [Mások] and the ads, and cruising on the streets. The eye-contact game, you know... and there were the bath-houses, of course. Then, as technology developed, people completely moved to the internet for finding new contacts (Edomer 38);* while the next generations could start to search for other gays already on the internet: *I started my gay life at the age of 17. I know my friends from internet chat-rooms or via other friends from a gay bar or a party (Alex 27).*

However, after becoming aware of their HIV infection, most respondents experienced significant changes in the size and intensity of their social relationships. On the one hand, they reported on feelings of isolation and the narrowing down of their old friendship circle: *There is no one left from my previous pre-HIV life. (Egon 40); Now that I got the HIV*

*infection, it became clear that I hardly have any friends (Krisztián 37).* On the other hand, there were references of new scenes for finding new friends, such as the hospital or the self-help groups. However, these “post-HIV friends” were more likely to be also HIV infected, and less likely to be “converted” from previous sex partners: *Today, the majority of my acquaintances are HIV infected (Feri 44); There are friends whom I met by the way of my HIV status, but there are some from before. These latter ones were “sexually transmitted” to me ... but later, from sex partners, we became very good friends (Herki 32).* The weakening of the social network embeddedness of people living with HIV/AIDS was common, at least relative to their situation before the disclosure of their HIV status, if that happened at all.

Most interviewees reported on the lack of support provided by family and friends after discovering their own HIV infection. Potential psychological damage resulting from a non-supportive family environment, manifested especially in the form of avoidance, is also highlighted by previous findings (Stutterheim 2009). However, avoidance by family could be explained partly by the fact that they had already grown very much apart from their families because of previous family conflicts, often related to their homosexuality and partly by the stigma associated with being HIV-infected or even knowing someone who is infected: *It is harder for them to have an acquaintance with HIV than for me acquiescing that I am infected with HIV ... I knew a gay guy from the countryside who was... in a tantrum saying that he does not want to be even close to me because the virus might jump from my skin to his (Edomer 38).*

On the other hand, participants who led a publicly more or less open gay life were more likely to communicate their HIV status to some of their friends and family members, and to get mainly emotional support from them. There was one rather exceptional case when a respondent decided not to disclose his HIV positive status in front of his elderly parents in order to spare them from worrying about him but, for practical reasons, he reported it at his workplace, where he turned directly to his boss who promised to keep his secret. This respondent explained that it was important that at least one person knew about his condition at work in case of a medical emergency.

### **(The lack of) Institutional support**

In Hungary institutional support for people living with HIV/AIDS is limited mainly to medical care provision. The fact that there is only one Hungarian hospital in Budapest with wards specialized on HIV/AIDS care, to which people are referred to from throughout the country after their positive HIV test results was perceived by several respondents as a source of problems: *At other places abroad, you can choose your therapist. Here, I cannot do this as there is no real choice. There are only two consultants and one resident. ... The one I got has a very strange style: ... if he has a bad day, he won't communicate with the patient at all. At the beginning, for example, no one told me that yes, you simpleton, you have to come back for testing every three months (Edomer 38).*

Anonymous HIV testing facilities were often mentioned as environments where people learnt of their seropositive status: *[Because of regular testing] it was easy for him [my sexual partner] to count the period during which he could have contracted the infection, and I was the only one in the picture... then I went for a test and it turned out that I am positive, too (Feri 34).* Those who got their positive result at an anonymous HIV testing facility were more likely to directly link with HIV medical experts because confirmatory tests are performed in the specialized HIV hospital. However, a better chance to get channeled into HIV medical care did not necessarily elicit sympathy or commiseration from the staff communicating the news: *The whole thing worked very much like an assembly line. They haven't bothered with treating your soul, not for a moment. They informed you that this is it and then bye-bye, let's have the next guy (Krisztian 37).*



There are several anonymous HIV testing facilities in Hungary, and an even larger number of STD clinics where free STD and HIV testing is available but only for those who can officially identify themselves. However, if a person gets a positive HIV test result, that person's identity must be disclosed in order for them to receive treatment. At present, all HIV/AIDS-related medical costs are covered by social health insurance, and this policy has been maintained in operation even during the recent global financial crisis.

### Recycled coping

Some interviewees believed that PLH should mainly seek each other's company. This seemed to especially characterize those who recently discovered their own infection. One respondent reported on how he contributed to the establishment of an informal self-help group for people living with HIV not long after he got his HIV-positive test results. For him, helping others to cope seemed to be an essential part of his own coping strategy.

Becoming active members in NGOs, mainly but not only in the field of HIV/AIDS care and prevention work, was often interpreted as a useful way to “*recycle coping experiences*” (Feri 44) and share these with others who are also in need. Another respondent who learned of his HIV infection only four weeks earlier emphasized that this was a period in his life when he would prefer the company of others also living with HIV: *I collected such a feature that can make me a very unpopular [lover]. Similarly to being old, it is not really cool to be HIV positive either (Etele 52)*. Already knowing other persons living with HIV usually affected how participants responded to the initial shocking news: *I did not think that this was the end of the world...I already had many [HIV] positive friends, so it wasn't an unknown thing for me. (Miki 42)*

PLH can experience social stigmatization not only by society at large but also by the often quite close-knit “gay circles”. Similar to previous findings of European qualitative work exploring the meaning of being HIV positive in the gay scene, we observed the uneven distribution of risk based on perceived and known HIV status in Hungary, dynamics of the gay scene that discourage HIV positive status disclosure (Flowers et al. 2000: 294). There was a general agreement among respondents that one should be careful in sharing information about being infected with others, as not everyone can be trusted and some might not have “*the intellect deserving to have this piece of information*” (Feri 44). Several respondents thus emphasized that they preferred to keep limited the circle of persons aware of their serostatus to prevent gossip: *If you tell the wrong person, it is like announcing it on television... It can lead to real problems in some places, and certainly at your workplace, if they found out... There [at my workplace], they don't know even that I am gay (Herki 32)*.

In most cases, main elements of coping included maintenance of secrecy combined with carefully deliberated trust concerning the disclosure of one's HIV positive status, reaching out for contacts with other PLH, and trying to “recycle” successful coping experiences in order to help others. Secrecy can contribute to the maintenance of one's social integrity by helping to avoid stigmatization but can also have serious negative consequences, including stress deriving from information management and leading a double life, limited access to different forms of social support such as self-help group activities, and potentially delayed enter into the healthcare system (Alonzo – Reynolds 1995). Additionally, hiding the HIV-positive aspects of one's life might become very tricky when starting a serious relationship, especially when it develops from a series of casual encounters that initially lacked prior disclosure of one's “HIV secret”. In fact, having a steady partner or a circle of friendly companions with whom one can be honest seemed to be one of the main sources of support for our respondents.

## Influence of stigmatization on intimate relationships and risky sexual practices

Fear of stigmatization following disclosure of one's HIV status in a sexual relationship, highlighted by previous studies (Kegeles et al. 1989; Alonzo – Reynolds 1995; Herek 2002), was also reported by our interviewees. Some chose to abstain from sex to avoid disclosing their HIV status; they reported on the long-term socially and sexually paralyzing effects of being diagnosed with HIV: *Almost one year after getting my diagnosis, I was still thinking that the best thing to do for me is to withdraw into my flat...waiting for my death... And, sometimes I still think and act this way (Rudolf 29); I did not have any sexual relationships for seven years (Gyuri 37).*

Some participants reported positive aspects of HIV status disclosure in intimate relationships: *There was this guy with whom I organized a meeting when I was still negative, but eventually we met only four days after I got my positive HIV result. To him I told that I became HIV positive. He was very shocked, but we still had sex. For me, it was a very unsettling and decisive experience: the fact that there is at least one person who wants me even in this state (Etele 52); Usually, I make it [my HIV status] clear on the net when I am looking for partners, and ... surprisingly there are those who do not turn away even when they know that I am [HIV] positive, and then we have sex, even if he is not positive... but we take care of each other (Elek 27).*

Some respondents emphasized that it took some time to get used to their own new seropositive personal and sexual character (Paicheler 1992: 22) and re-learn as well as reinterpret certain sexual practices: *After the sexual act, he announced that it was a good thing that we used a condom... this way, he gave up some part of his responsibility by clarifying the situation. This could help him to dissolve a part of his fears, but at the same time it also made him very vulnerable. On the other hand, during having sex... there is this lookout, a much focused attention on what's going on, it is not focused on sex itself but on potential forms of infection – and if he keeps the knowledge of his infection for himself, he will be the only one who will activate this potential infection sensor... If both of us try to do that, it can be too much... well, if two people love each other, it can work but you need a lot of practice for that (György 30).*

In the interview narratives, we encountered signs of what was described in previous studies (Gold 2004; Nemeroff et al. 2008) as “fatalistic beliefs” and “unrealistic optimism” concerning the likelihood of becoming infected. Different elements of HIV-related cognitive avoidance could be identified, including fatalism or short-term thinking, thought suppression and distraction, as well as alcohol and drug use: *It has never occurred to me that I can get infected... never... I blocked this center [in my mind], which could sense danger... suppressed it ... with drugs (Krisztián 37); My first boyfriend with whom I lived together [abroad] was a social worker who worked with HIV positive people, and he was [willingly] not able to tell about himself whether he was HIV positive or negative [because he didn't want to know]. He simply refused to be tested (György 30).*

One respondent placed the issue of cognitive avoidance into a socio-historically specific context: *I believed that my partners were clean, and thus there wouldn't be any problem. It wasn't a very elegant topic to talk about in the 1980s. Most people were not even aware of how HIV can be contracted... and I wasn't interested. ... Stupid me, I kept telling myself that it cannot happen to me, as I pick my partners carefully – [but] I misunderstood the whole thing... I believed that I have the ability to recognize the signs [of infection]. I look through my partner and, if I haven't found any of these ugly red spots, I was ready to conclude that there is no problem, [so] no need for condom use (Egon 40).* This account reflects the Hungarian situation of more than a quarter of a century ago when there was a much greater scarcity of information about HIV/AIDS than today. It should also be added

that, in a practically as well as cognitively isolated state-socialist country like the former Hungary, general strategies of cognitive escape were widespread social practices, applied well beyond the issue of HIV/AIDS.

Different types of fatalistic beliefs were present when people reported certainty that they would become infected, because of their regular involvement in risky situations that posed realistic risk. Sex parties with large numbers of sex partners and drug use, and “unusual sexual practices” were sometimes reported and led to this fatalism: ... *it happened at a sex party where I protected myself [with a condom] but I got scrapes on my back and I laid in everything... sperm, blood... as it was a long party... and I knew that the host is seropositive, and I assumed that his friends are also infected* (Tomi 30); *It was freaky [to know that I got infected]. I wouldn't say that I have been preparing for it... but it has definitely crossed my mind as I am practicing unusual sexual acts: ...hard sex, sadomasochism, fisting* (Ákos 22).

Previous research findings (Shuper et al. 2009; Bird – Voisin 2010; Benotsch et al. 2011; Obermeyer et al. 2011; Stutterheim et al. 2011) highlighted potentially different motivations of HIV-positive and negative partners for practicing safer sex, with HIV-positive partners believed to be influenced by more altruistic norms concerning the avoidance of HIV transmission, while HIV negative partners seen as influenced by the more egoistic desire of self-protection. According to our interviewees' reports, the main method to try remaining safe before their infection often seemed to be avoiding infected partners, either by not having sex with those who disclosed their positive HIV status or by having sex only with trusted, and often loved, partners: *In (gay) bars, if I knew that someone is HIV positive, I would rather avoid him* (Krisztián 37). However, these strategies often proved to be unreliable: *No one told me at the time that he would be one [HIV positive], but now I know for sure that I must have had sex with positive ones quite a few times* (Tomi 30); *It was my ex who infected me, but at that time I didn't know about [his HIV infection]* (Zsiga 40); *I got infected from my boyfriend. I trusted him. ... I won't leave him because of his HIV status, as hopefully he won't leave me now because of mine [laughter]* (Móric 31).

When asked about how they introduce changes in the protection level of sexual practices after learning of their own positive HIV status, respondents reported different levels of disclosure to their partners: *Well, I tell those [about my HIV status] with whom I have sex... because I do not want to ruin their life by potentially contracting a new infection from me* (Zolcsi 26); *There is this guy I had sex with just before I was tested positive but I haven't told him as yet [about my infection]... I am still thinking of telling him or not telling him. But then he will blame me that he got the infection from me though it wouldn't be certain at all whether it is the case as he is rather promiscuous* (András 34). In some cases, shared responsibility and mutual agency of the partners were emphasized, and protective measures were completely avoided: *It does not affect me [my HIV status]. Of course, I have sex. If the partners venture it, we do it without a condom. But, I do it without condoms only with other HIV positives. Well... and also with these last two HIV-negative [I didn't use a condom] but only because they wanted it that way* (Alex 35).

## Discussion

Consistent with international qualitative research findings in the field of HIV/AIDS prevention, the present study contributes to a fuller understanding of how sexual behavior, risks and risk perceptions, together with homosexuality and HIV/AIDS-related stigma and social exclusion mechanisms, are structured in previously under-researched socio-cultural settings (Abramson – Herdt 1990). In interviews conducted with self-identified gay men living with HIV/AIDS in Hungary, references to concurrent experiences of both HIV/AIDS-

and homosexuality-related stigmatization were common. Most respondents who did not experience any forms of social exclusion related to sexual orientation and HIV infection kept these aspects of their lives concealed. There was generally more secrecy about being HIV infected than about being gay, and keeping one's HIV-secret was seen as a practical strategy of self-protection from manifestations of enacted stigma. In general, secrecy was seen as a strategy to avoid stigmatization. Potentially negative consequences of secrecy such as stress from double-life management, was not emphasized by our respondents. Hiding one's HIV positive status usually became hard when beginning a steady relationship, especially if it had been preceded by casual encounters with the same partner. In the interview narratives, fear of stigmatization inhibited disclosure of one's HIV status in a sexual relationship. Prior to contracting HIV, study participants reported that they primarily avoided infected partners, either by not having sex with those who disclosed their HIV-positive status or by having sex only with trusted partners. However, these proved to be unreliable methods.

Participants often encountered HIV/AIDS discrimination and stigmatization experiences in environments where their HIV status could not be concealed. The healthcare system was an environment where they encountered various forms of antagonism, including negative attitudes and avoidance, from healthcare providers. This finding is consistent with results of a recent targeted community survey, where 28 percent of 1,122 Hungarian LGBT respondents reported encountering discriminative treatment in the healthcare system (Takács et al. 2008).

There were similarities between our respondents' reports with discrimination experiences with those of PLH in other post-socialist countries (Amirkhanian et al. 2003; Novotny et al. 2003; Rhodes – Simic 2005; Štulhofer et al. 2008; Bernays – Rhodes 2009; Bernays et al. 2010). The similarities illustrate the disempowering effects of HIV/AIDS stigma especially in denial of access to work either by being fired from workplaces or not being hired for jobs. Refusal of general and HIV-specific health care, on the other hand, was not common in our sample. In Hungary, free universal HIV treatment access is provided, at least as far as patients accept services in a hospital specialized for contagious diseases and assigned for HIV patients. Additionally, none of the Hungarian interviewees reported being forced by the police or healthcare practitioners to provide sensitive information on themselves or their partners and, unlike some of the participants in a Russian study (Amirkhanian et al. 2003), they did not have to sign statements declaring their HIV infection.

A previous study focusing on HIV vulnerability in Central and Eastern Europe identified several barriers to effective HIV prevention programs, including the lack of infrastructure to support national HIV/AIDS prevention efforts, country-specific socio-political and cultural climates where HIV/AIDS infection is pictured basically as a moral (or rather immoral) issue, and the continued high stigmatization that makes it hard reach vulnerable groups by community programs (Amirkhanian 2011). The existence of these barriers in Hungary was also highlighted by our findings. Most interviewees reported on the lack of support provided by family, friends, NGOs, or the state. Institutional support for people living with HIV/AIDS is limited mainly to medical care provision in present day Hungary. The only Hungarian governmental body, the National AIDS Committee, established by the government to coordinate HIV/AIDS prevention and treatment, and to consult with relevant state and non-state stakeholders, does not carry out specific programs designed to socially integrate or re-integrate MSM living with HIV/AIDS. Although sex between men is the predominant mode of HIV transmission in Hungary (OEK 2011) and which the European Centre for Disease Prevention and Control emphasizes the need to strengthen HIV prevention interventions for MSM in Central Europe (ECDC 2011), there are no public health programs specifically targeting MSM in Hungary. This lack can be interpreted as a

consequence as well as a public manifestation of social stigma affecting MSM in the context of HIV/AIDS prevention and treatment.

This study's findings identify several changes to improve the present situation. These include lessening the adverse effects of HIV/AIDS- and homosexuality-related stigma within the gay community, the general population and especially among service providers. In general, efforts are needed to raise awareness that social isolation can lead to high risk behavior. Lack of interpersonal and social support can inhibit risk reduction behavioral change by gay men living with HIV/AIDS. HIV/AIDS related issues have to be presented in a manner acceptable by PLH themselves who are most directly affected by HIV/AIDS policies and portrayals. In this context, a very relevant issue is how to improve the willingness of people in general, and MSM in particular, to get tested. Special programs are needed to increase rates of HIV-testing and minimize the inhibiting effects of stigmatization that might prevent MSM from seeking HIV testing.

Application of various forms of awareness-raising, including information exchange, education, training, and personal involvement opportunities, can facilitate the development of programs to better integrate PLH into support networks. Nongovernmental organizations are in a position to provide space, infrastructure and initiatives for organizing such networks, especially when help from family and friends is scarce. However, to achieve these ends, NGOs need sustained financial support from the state. Governmental bodies, such as the National AIDS Committee, should initiate programs to facilitate the social (re)integration of PLH by organizing campaigns against homophobia and social exclusion, targeting the general population as well as healthcare providers. The role of service providers is especially crucial as they have, at least in theory, a good chance to build trust based relationships with PLH clients. Healthcare providers will benefit from sensitizing and de-stigmatization training focused on HIV/AIDS and patient care-related issues including the mental health needs of their clients and patients. Specialized training for primary care practitioners would also be beneficial to increase recognition of symptoms of HIV/AIDS, comfort in nonjudgmentally discussing sexual behavior, and offering testing. Healthcare providers could more actively increase social support for PLH clients by encouraging their participation in existing support groups. In addition to direct medical care, social and psychological service support and health promotion should be also more accessible in HIV care settings. Additionally, governmental and non-governmental efforts contributing to a fuller social integration of people living with HIV/AIDS should be effectively coordinated for high cost-efficiency and quality.

## Limitations and conclusion

This study has several limitations. One of the main limitations derives from the use of a self-selected convenience sample that does not allow generalization of study findings to the larger population of Hungarian gay men living with HIV/AIDS. The majority of participants was active in the local gay scene or in HIV/AIDS self-support groups and may not be representative of the MSM population in general. Another limitation arose from potentially sensitive issues raised during interviews, such as personal feelings about social ostracism. Psychological and emotional barriers may have prevented some participants from verbalizing their experiences. Thus, not all aspects of each individual's experiences and behaviors relevant to stigmatization and stigma management could be explored and documented to the same extent. Participants were also characterized by different levels of self-reflection and diverse forms of coping mechanisms, and these did not always yield possibilities for a detailed examination of the circumstances and motives for their behavior. However, and in spite of its limitations, this study contributes to a better understanding of the patterns of social functioning and stigma management strategies of gay men living with HIV/AIDS in a stigmatizing social environment.



At present Hungary is still a low-prevalence country. Thus, this is exactly the best time to introduce prevention measures helping to avert a more widespread epidemic and keep infection incidence as low as possible. Social exclusion and stigmatization mechanisms must be taken into account when designing HIV/AIDS prevention programs at the local level. Secrecy, as the main means of stigma avoidance, can lead people to get involved in risky social and sexual activities, such as leading a double life and engaging in unprotected sex. Effective HIV/AIDS prevention and care programs thus need to address HIV/AIDS- and homosexuality-related stigma avoidance issues in Hungary and elsewhere.

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